Provincial Health Officer's Report on HIV Reportability

P. R.W. (Perry) Kendall, MBBS, MSc, FRCPC

Provincial Health Officer

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Summary

In January 2000, the Health Officers Council of British Columbia reviewed a discussion paper authored by Dr. Patricia Daly and Dr. Robert Parker (Appendix A) on the rationale for adding HIV infection to the list of reportable conditions under Schedule A of the Health Act Communicable Disease Regulation. Health Officers Council subsequently passed a resolution requesting the B.C. Communicable Disease Policy Advisory Committee to recommend to the minister of health that HIV be made a reportable condition and added to Schedule A.

The B.C. Communicable Disease Policy Advisory Committee reviewed the issue and failed to reach a consensus. As Chair of the Committee, the Provincial Health Officer undertook to perform a more detailed review and a community consultation process, report back to the Committee, and make recommendations based on findings and consistent with the Provincial Health Officer's legislative role under the *Health Act*. Dr. Timothy Christie assisted in the review and consultation process.

Consultations were initiated with a range of stakeholder groups, including:

- AIDS service providers
- Persons living with HIV/AIDS
- People who use injection drugs
- HIV-positive women
- Women's Health Bureau
- Representatives of B.C. Children and Women's Health Centre
- College of Physicians & Surgeons
- B.C. Centre for Disease Control
- Red Road HIV/AIDS Network Society, as well as Aboriginal leaders
- The Minister's HIV/AIDS Advisory Committee
- Minister's Advisory Council on Women's Health
- YouthCO AIDS Society
- Other community groups

Stakeholders' views, which are almost unanimous in opposing reportability, are presented in this report, including an appendix containing written submissions (Appendix B).

The published literature on the impact of reportability suggests that the main benefits accrue in the areas of enhanced epidemiological surveillance and partner notification. It is clear that improved partner notification substantially shortens the time from infection to diagnosis, and is generally appreciated by those identified and counseled.[1] However, beneficial impacts on HIV epidemics, i.e., diminished spread of the disease, are not established.

The potential adverse effects that are raised in objection to making HIV reportable are not substantiated in the literature. Examples of objections include: that it is accompanied by breaches of confidentiality, reluctance to

[1] For a review of the literature on partner notification, see pages 23-24.

come forward for testing, avoidance of testing, and increases in repressive measures against HIV infected persons. Nonetheless, these remain valid concerns that should be addressed in any public health schema for HIV disease prevention and control.

A review of the current reporting system in B.C. suggests that the main benefits of reportability of HIV in this province would be in the area of partner notification, with a potential shortening of the time from infection to diagnosis and treatment/counseling. This would, however, be contingent upon a reallocation of resources to index case interviews and subsequent partner notification. The consultation raised several issues of concern around the present system of HIV diagnosis and follow up, and these will be addressed in the report.

British Columbia and Quebec are distinct in Canada as the only provinces that do not require reporting of HIV, with identifiers, under their public health legislation. In all other provinces and territories, and in the majority of U.S. states, HIV infection is a nominally-reportable condition.

Recommendations

1. HIV should be added to the list of reportable conditions in Schedule A of the Health Act Communicable Disease Regulation.

2. A non-nominal option should be available for persons being voluntarily tested who do not wish their names to be reported to the public health authority.

3. Physicians, other health professionals, and all persons likely to view HIV test results should be informed of their duty under the *Health Act* to maintain confidentiality around the information contained in such reports.

4. Physicians and other persons offering HIV testing should be aware of the requirements for informed consent and the necessity of adequate pre-test counseling.

5. Adequate resources must be available for patient counseling and partner notification, counseling, and follow up.

6. Best practices protocols for enhanced partner notification should be developed and disseminated, and the process of public health partner notification should be subjected to continuous quality control.

7. The impacts of making HIV reportable should be the subject of an evaluation. If the net impact is determined to be a negative one (as measured against preset criteria), steps should be taken to remedy specific problems, or HIV should be taken off the list of reportable conditions.

Proposed Process for Public Health Involvement if HIV Reportable

1. Individual approaches the provider for testing.

2. Provider counsels on nominal/non-nominal options and implications of reportability if result positive, i.e., public health involvement and opportunity for voluntary, anonymous partner notification.

3. Provider gets consent to test.

4. Test carried out at provincial laboratory (B.C. Centre for Disease Control). Positive tests reviewed to eliminate duplicate test results.

5. If test result is positive, B.C. Centre for Disease Control staff call the referring physician to confirm epidemiological data and risk factors, offer resources, and inform about public health involvement in partner notification.

6. Positive tests referred to regional medical health officer.

7. Regional public health nurse contacts physician to discuss case and offer assistance with contact naming. Public health nurse contacts patient if permitted; otherwise, takes contact names from physician. Public health nurse does partner follow up.

8. B.C. Centre for Disease Control continues to compile aggregate statistics, informed by enhanced local epidemiological follow up. Local health authorities compile regional statistics.

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The Provincial Health Officer gratefully acknowledges Dr. Timothy Christie, Manager, Clinical Services, Community Health Services, Vancouver/ Richmond Health Board. Dr. Christie assisted in the consultation process and authored Part Two and Appendix E of this report.

Thanks are owed to the following individuals, who reviewed drafts of this report and provided constructive comments and suggestions: Lisa Allgaier, Dr. Nelson Ames, Dr. David Bowering, Dr. Patricia Daly, Dr. Marian Hutcheon, Dr. David Martin, Dr. Deborah Money, Renee Nyberg-Smith, Dr. Michael Rekart, and Lorna Storbakken.

The Provincial Health Officer also thanks the many individuals and groups who met with him to discuss and debate the issue of HIV reportability.

PART ONE

Present and Proposed System of HIV Reportability in British Columbia and Report on Consultations

Introduction

The public health system has a tradition of assisting individuals who have communicable diseases, both to improve the health of the infected person and to reduce the risk of infection to others. Communicable disease control is considered so important to the health of the population that, for selected diseases, public health interventions are enshrined in legislation, primarily the *Health Act* and its Regulations. Notification to public health authorities of cases as they occur is a key method of collecting the information needed to prevent and control such diseases.

AIDS, the last phase in HIV disease, has been a reportable disease in British Columbia since January 1983, when British Columbia became the first jurisdiction in the world to designate AIDS as "notifiable."[1] HIV infection is not currently reportable in this province. However, testing data provide a view of disease trends and patterns.

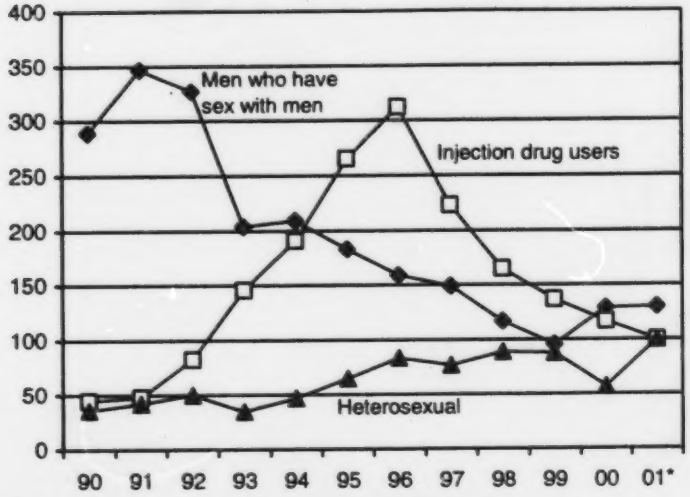
Epidemiology of HIV in B.C. 1990–2000

Overall, the rate of new HIV infections has been declining in B.C., from 20 per 100,000 in 1990 to 10 per 100,000 in the year 2000. These figures are based on those who are tested for HIV and do not represent the total number of people who were infected with HIV during this time period, as some HIV-positive people will not have been tested.

The changing nature of the HIV epidemics in B.C. is readily appreciated from Figure 1. During the decade 1990-2000, the epidemic of HIV in men who have sex with men peaked in 1991 (347 new positive cases), then declined steadily and consistently year over year until 1999 (99 cases). In 2000, HIV incident infections started to demonstrate a worrying resurgence in this community. Preliminary figures for 2001 indicate that this trend is continuing, with a projected total of 130 cases.

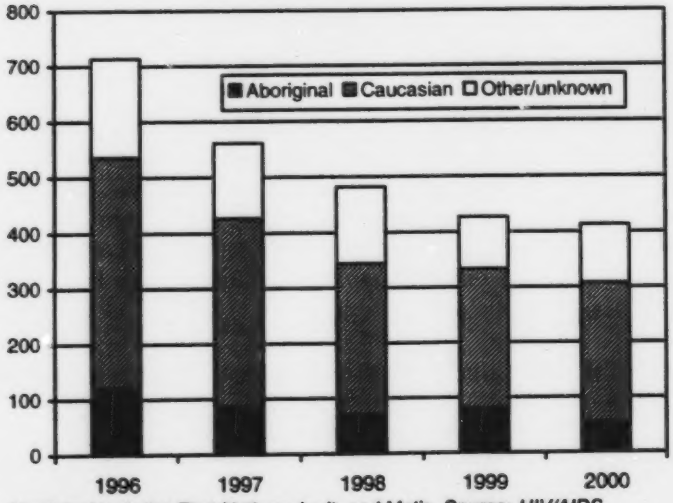
The epidemic of HIV in persons who use injection drugs peaked in 1996 at 312 new positive cases (see *Pay Now or Pay Later*, a 1998 report by the Provincial Health Officer[2]). The number of new cases has since shown steady declines, but remains at unacceptable levels of transmission. Results from the Vancouver Injection Drug Use (VIDUS) study showed the HIV new infection rate to be about 2 per 100 person-years in 2000.[3]

Figure 1
Persons Testing Newly Positive for HIV
by Risk Category, B.C., 1990 - 2001



* Projected, based on totals for January to October 2001.
Source: STD/AIDS Control, B.C. Centre for Disease Control Society.

Figure 2
Persons Testing Newly Positive for HIV
by Ethnicity, B.C., 1996 - 2000



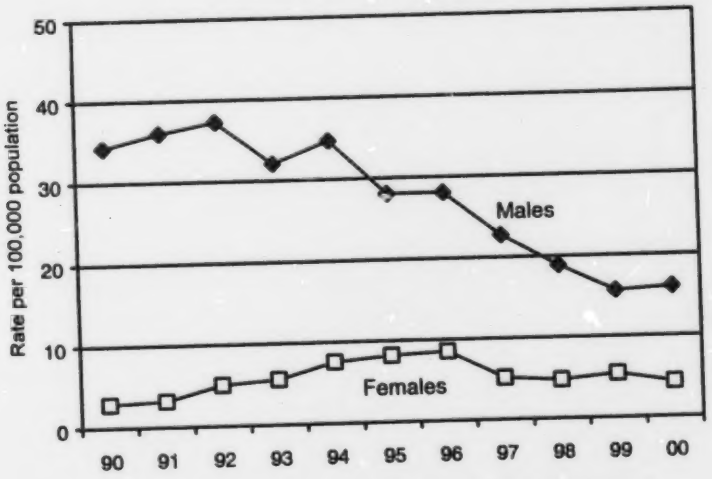
Aboriginal includes First Nations, Inuit, and Metis. Source: *HIV/AIDS Update Semi Annual 2001*. STD/AIDS Control, B.C. Centre for Disease Control Society, June 30, 2001.

Heterosexual infection has had the lowest incidence of the three epidemics, representing just under one-third of new cases in 1999, then showing a slight decrease in 2000. However, this mode of spread is resurgent in the first ten months of 2001. If the trend continues, 100 cases will be reported this year, and heterosexual spread may overtake injection drug use as a risk behaviour for HIV.

Regionally, Vancouver has the most cases – 242 of the 413 new positive cases reported in the year 2000. However, new HIV-positive cases occur in all regions of the province. Aboriginal people comprise approximately 16 per cent of those testing newly positive, based on tests since 1996 (Figure 2). Aboriginal people are disproportionately affected by HIV/AIDS, given that 4 per cent of the population identified as Aboriginal in the 1996 Census.[4]

Males outnumber females in the number of new HIV infections, although the ratio is changing. The rate of HIV infection has been declining in men, while in women, the rate has increased (Figure 3). Women accounted for 89 (22 per cent) of the 413 new positive cases reported in 2000.

Figure 3
Persons Testing Newly Positive for HIV
by Gender, B.C., 1990 - 2000



Source: *HIV/AIDS Update Semi Annual 2001*. STD/AIDS Control, B.C. Centre for Disease Control Society, June 30, 2001.

Since 1994, the Ministry of Health has recommended that all pregnant women be offered testing and, if indicated, treatment for HIV, to reduce the risk of mother-to-child transmission. In 2000, 23,408 women – about 60 per cent of all pregnant women – had HIV testing as part of their prenatal

assessment.[5] Since prenatal testing was introduced, 155 pregnant women have been diagnosed as HIV-positive, either during or prior to their pregnancy. To date, there have been no cases of maternal-child transmission among screened women who received treatment for HIV. However, the Oak Tree Clinic is aware of 17 HIV-infected infants born since the screening program began.[6] These babies were born to mothers who were either not screened, did not receive antenatal antiretroviral therapy, or were out of B.C. at the time of delivery.

Testing

All laboratory testing for HIV is performed at the B.C. Centre for Disease Control Laboratory (formerly the Provincial Laboratory) and has been since 1985 when testing was first licensed.

Samples from patients are sent to B.C. Centre for Disease Control (BCCDC), where preliminary and confirmatory testing is performed. Staff at BCCDC review all positive results, attempt to eliminate or account for duplicate test results, and abstract epidemiological data. Referring physicians are contacted in order to i) offer resource materials to referring physicians ii) obtain missing epidemiological data iii) offer assistance with partner notification. The epidemiological data are then transferred to a non-nominal database and become part of the ongoing provincial HIV reports. Non-nominal aggregate data also become part of the regional HIV databases.

Some idea of testing volume may be obtained from data for the year 2000, when total test volume was 135,488, of which 413 were persons who were newly positive (persons who tested HIV-positive for the first time).[5]

Present status of nominal identifiers

At present 80 per cent of test requisitions bear personal identifiers. Of subsequent positive requisitions, 80 per cent bear personal identifiers. However, only 36 per cent of nominal positive tests carry risk information, compared with 82 per cent of requisitions that do not carry names (M. Rekart, personal communication, June 2001).

Assessment of System in B.C. Centre for Disease Control

British Columbia is widely acknowledged as having one of the better HIV data sets in Canada. This is directly attributable to the staff at the B.C. Centre for Disease Control, who are lauded by community-based AIDS organizations for their activities. Epidemiological information is ultimately available on 85 to 90 per cent of incident HIV tests.

The B.C. Centre for Disease Control has made continued improvements to HIV surveillance by enhancing and making better use of available

information. However, it is argued by Health Officers Council that knowledge of HIV in B.C. could be improved by more accurate geographic case assignment and enhanced local epidemiological analysis.

In 10 to 12 per cent of cases, it is unknown to BCCDC whether test results are given to patients. In 10 per cent of cases, it is known that results have not been given to patients. Patients in this category are mostly persons who use illicit drugs.

While not tabulated by BCCDC, it is estimated that only a small minority (2 to 3 per cent) of physicians request assistance with partner notification and contact tracing. Provincially, there are no data on the extent to which partner notification occurs. Initiatives by BCCDC to involve public health in enhanced partner notification pilots have not been successful to date.

The present system of data collection and reporting is consistent with the general purposes of BCCDC through the delegated *Health Act* functions of the Provincial Health Officer. There is no specific legal mandate at present for assisting with partner notification or for other activities related to look back/trace back programs with agencies such as the Canadian Blood Service.

Health Officers Council Proposal

In early 2000, the Health Officers Council of B.C. supported the recommendations of the report authored by Drs. Daly and Parker (see Appendix A) that HIV be added to the list of reportable diseases under Schedule A of the Health Act Communicable Disease Regulation. Health Officers Council supported HIV reportability on three grounds:

1. Mandatory reporting of HIV information to local medical health officers would enhance the local (and hence provincial) epidemiological profiles, improve local knowledge and awareness of HIV/AIDS, and better equip local health authorities to assume their responsibilities in responding to HIV/AIDS.

2. Contingent on the above, knowledge at the local level of individual cases and risk behaviours would better equip the health authorities to provide improved access to prevention, treatment, care, and support. This would include planning for the provision of care to those individuals (mostly injection drug users) who are presently under-represented in the anti-retroviral therapy registry.

3. Knowledge of incident infections and a legal mandate would enable public health to improve case counseling, partner identification, partner notification, and subsequent access to testing, treatments, and support.

Background - HIV reporting in Canada

In 1985, Ontario became the first province to make HIV reportable under its *Health Protection and Promotion Act*. Other provinces and territories followed suit, with three exceptions: British Columbia, Alberta, and Quebec. In 1997, the Canadian Public Health Association passed a motion requesting the ministers of health for British Columbia, Alberta, and Quebec to make HIV reportable in their provinces. [7]

By 2000, with the exception of B.C., all provinces and territories have made HIV reportable. Details on reportability vary, with Ontario offering nominal, anonymous, and non-nominal reporting options, and Quebec mandating only non-nominal reporting.

Following a review by the B.C. Communicable Disease Policy Advisory Committee, the Provincial Health Officer, Chair of the Committee, committed to undertake a public consultation with those groups most affected by HIV/AIDS and to prepare a report, with recommendations, under his authority under Section 3 of the *Health Act*.

Community Consultations

Consultations occurred over an extended time period during 2000 and 2001. The process was iterative. The Health Officers Council paper was circulated and presented to groups and individuals, discussions took place, and concerns and responses were presented at subsequent meetings. The results are summarized in this report (for written submissions, see Appendix B).

Although the consultations were not exhaustive, most groups raised the same general and specific concerns. I believe, therefore, that the consultation was successful in surfacing a comprehensive set of issues. Few if any concerns would not have been identified.

I would like to express sincere appreciation to the groups and individuals who met with me to discuss and debate the proposal. I thank them for enriching the process, and although I anticipate most, if not all, will disagree with my conclusions and recommendations, I trust any further round of discussion will be marked by the same mutual respect that has characterized our discussions to date.

Community and AIDS service organizations responses to the proposal of HIV reportability can be grouped as follows:

- Issues for which support was expressed
- Issues for which some support was elicited
- Issues around which serious concerns were expressed

Support

1. Support was generally expressed for the notion that better epidemiological data will assist in addressing HIV/AIDS prevention and support planning. However, it was pointed out that this could be achieved without mandating reportability.

2. There is universal support for voluntary HIV testing with informed consent.

3. There is universal support (demand) for protection of privacy and confidentiality.

4. There is agreement that more supports are needed for HIV infected people, better access to care is required, and enhanced prevention is a necessity.

5. There is support for enhanced programming and greater attention to be paid to the needs of marginalized communities, aboriginal people, youth, and women.

Some Support

Some support was expressed by some individuals for:

1. Assistive programs for partner notification and referral if i) they are voluntary ii) they are confidential iii) they are based on best practices and subject to continuous quality monitoring.

2. Increased public health resourcing and involvement in supportive and assistive programming, as long as privacy, autonomy, and beneficence are the guiding principles of public health involvement.

3. The concept that there exists an ethical duty to inform contacts at higher risk, especially if these contacts are likely not to appreciate their risk status.

4. The concept that there exists an ethical duty not to put others at risk.

Concerns

Community groups universally expressed concerns that:

1. The confidentiality of test results would be breached by a mandatory reporting requirement.

2. This would lead to a fear of testing and non and/or delayed testing.

3. That HIV-positive people would be subjected to further discrimination by the public health system or other organs of the state.

4. That HIV-positive persons would be subjected to coercive measures by the state, either to change behaviours or to name partners.

5. That sanctions would be applied to persons who would not, or could not, comply with recommendations to change behaviours or notify partners.

6. Reportability requirements would have particular negative impact on aboriginal people, women (or men) in abusive relationships, street oriented youth, and persons living in smaller communities.

Issues Raised

A number of issues were raised during the consultations that clearly reflect the reality for many persons living with HIV/AIDS. These issues are serious enough to warrant inclusion in this report.

1. Confidentiality and Informed Consent Concerns

The experience of persons living with HIV/AIDS or acting as their supporters or advocates is that the health care system does not in all instances honour the principles of informed consent, voluntary testing, and confidentiality.

I was assured by many of the individuals that there were many occasions on which individuals had been tested for HIV without their express consent. This is reported to be a bigger problem for women, marginalized individuals, e.g., persons who inject drugs, and youth. Concern was expressed that any proposed reporting schema could result in already stigmatized individuals being faced with further violations of the principle of voluntariness, and subsequently with unexpected intrusions from the state.

In small communities, clinic staff are known by the person being tested. Individuals may be reluctant to be tested, even if confidentiality is maintained. I was assured that for many, particularly those living in small communities, breaches in confidentiality are perceived to be commonplace. Physician office staff, health assistants, laboratory workers, nurses, pharmacists, pharmacists assistants were all cited as individuals who, in the experience of persons with HIV, had breached confidentiality.

This was cited as a particular issue for Aboriginal people, whose communities may have different expectations around what is the community "right to know" compared to individual privacy rights, than do non-aboriginal communities. This was confirmed at a meeting with senior First Nations officials, where the (minority) opinion was expressed that communities needed to know the identities of those infected so that "they could take protective measures."

How this issue should be addressed is beyond the scope of this report, but is rather an issue for the Aboriginal community to resolve, and I recommend further discussion within the Red Roads HIV/AIDS Network Society. However, the confidentiality provisions that pertain to reportable communicable diseases under the *Health Act* apply to all British Columbians, including First Nations people and their caregivers.

The results of these experiences are that many, perhaps most, individuals in smaller communities in B.C. do not seek testing or care in those communities, but are forced to seek these services in larger communities. This is an inequitable barrier to care. It also skews the perception of the epidemic and forestalls the development of prevention and care programs in these communities. As an example, I was told by a nurse working with the Vancouver Native Friendship Centre that she knew of several communities who stated categorically that they "had no HIV problems," while she had members of those communities on her caseload.

It is ironic that the breaches in confidentiality that are cited as reasons against making HIV reportable occur without any apparent sanction or route of redress in the present non-regulated reporting environment. Were HIV to be listed under the *Health Act* regulations, breaching confidentiality would be a serious offence. Under the *Health Act*, penalties of up to $200,000 or 12 months in jail might be levied (see Appendix C for legal opinion and Appendix D for *Health Act* provisions and penalties).

I raised these issues with the Ministerial Advisory Committee on HIV/AIDS and also with the Human Rights Commissioner. Irrespective of the issue of HIV reportability, these issues must be addressed. It should also be noted that in contradistinction to the anecdotally reported breaches of confidentiality, there is an absence of reported breaches of confidentiality arising from within the public health system.

2. Reporting as a disincentive to testing

What Canadian data are available (personal communications from Ontario and Alberta) do not support an adverse effect of reportability on HIV testing overall or in any sub-population. Such an adverse impact may have been averted or mitigated by provisions in the respective Regulations that have created anonymous and non-nominal reporting options. In Ontario between 5 and 10 per cent of test requisitions are submitted under the anonymous option, and gay men are the most likely to seek this option (E. Wallace, personal communication, June 2000). Recent implementation of nominal reporting in Alberta, again with an anonymous alternative, has not been accompanied by any decline in testing (B. Larke, personal communication, January 2001).

A comprehensive review of the impact of nominal reportability in the U.S.A. similarly finds no consistent adverse impact, either overall or in any specific sub-population when post-reportability testing requisition numbers are

compared with pre-reportability testing data. The literature suggests that delays in testing are more likely due to apprehension about subsequent test results than concerns over public health involvement.[8,9,10,11]

I recommend that in consideration of this potentially adverse effect on testing behaviours, a non-nominal reporting option be included, should HIV be made reportable. The necessary public health follow up can be performed as long as cases can be individually identified through referring physicians. As noted previously, nominal testing is the norm at present, with 80 per cent of HIV requisitions carrying this information.

3. Concerns over stigmatization and coercion

Concerns over stigmatization of persons with HIV/AIDS are a reality and need to be continually addressed. There is, however, no evidence that making HIV reportable has contributed to further stigmatization in any jurisdiction. Coercive public health measures against persons who knowingly spread communicable diseases or agents causing a reportable communicable disease (which definition includes AIDS) are presently within the powers of medical officers of health under Section 11 of the B.C. *Health Act*. As these powers presently apply to HIV, they would not be affected by the reportability status of HIV. The experience in B.C. after more than 15 years of HIV epidemic activity is that these powers are used extremely rarely and are subject to extensive checks and balances.

4. Concerns over negative impacts on persons (predominantly women) living in abusive relationships.

The scenario was raised that an HIV-positive woman (or man) in an abusive relationship is tested and her (his) results are provided to the local public health authority, who in making contact with the woman (man) alert the partner to the HIV issue. The subsequent destabilization of the relationship could then lead to further violence or in the extreme, death for the woman (man). This scenario is not, of course, limited to HIV. There are a number of more prevalent diseases, such as gonorrhoea, chlamydia, and hepatitis B, for which partner notification is standard.

While in no way minimizing this concern, I submit that the solution to the problem posed does not lie in not involving public health, but in involving the resources of public health in a sensitized and collaborative way. In the case pictured above, the woman needs enhanced supports and counseling and very careful consideration by public health of the risks involved in partner notification (which may be contraindicated). In addition, consideration must be given to how the resources may be marshaled when the abusive partner does come to learn of his partner's status, which may be through means unrelated to public health involvement.

In sum, known infection of one partner with a communicable disease, in an abusive dyad, requires proactive planning and sensitive intervention strategies, whether or not HIV is reportable.

Guidelines for index case follow-up will need to include detailed protocols as well as local arrangements between public health officials and agencies providing support to abused persons. There is a substantial Canadian experience on which to draw, and I recommend that protocols for addressing this situation be drawn up by organizations with the requisite expertise. In recognition of this sensitive area, my office has in some instances advised medical health officers not to pursue public health involvement when the risks to the abused partner were deemed to be both excessive and unmitigatable.

Additional Considerations

Resource implications

A commitment to follow up of index cases clearly requires a concomitant resource allocation. Based on an estimated 400 incident cases per annum, of which 40 per cent on interview might identify an average of two to three partners each, a workload of between 400-500 cases for follow up might be anticipated. Assuming one full time equivalent public health nurse can case manage 80 to 100 follow up cases per annum, a minimum additional 5 FTE positions would be required for the workload.

Alternative option proposed by community groups

The reasoning and tentative conclusions of this report were presented in draft form to a variety of HIV/AIDS-serving organizations. These organizations considered the HIV reportability recommendation in detail, and their responses can be summarized as follows. Rather than making HIV reportable and using that as a strategy to enhance informed consent, confidentiality, partner notification and referral, the deficiencies identified through this consultation should first be addressed. Only if this voluntary strategy failed should reportability be considered.

I have examined this argument, and I respectfully submit that, if in the 16 years since HIV antibody testing was introduced into this province, we have reportedly failed to ensure universally informed consent or universal respect for confidentiality and have not been able to develop a consistent, evaluable partner notification program, we are unlikely to be able to do so in the immediate future without a defined legal framework and contingent ethical obligation. I further submit that the changing nature of these HIV epidemics makes it a priority to intervene, provide enhanced counseling to index cases and identify, contact, and counsel their partners. This is consistent with the 2001 Centers for Disease Control Serostatus Approach to Fighting the

Epidemic (SAFE). SAFE is an approach that focuses on increasing the number of persons who know their serostatus and helps infected persons reduce the risk for infection with HIV and provides referrals for HIV infected persons to medical care.[12]

The alarming, recently documented increase in B.C. in male-to-male HIV transmission and the continuing steady spread in the heterosexual community demand more of a public health response than we are presently providing. I therefore recommend that an enhanced and targeted educational program be initiated to focus on the risk communities and risk behaviours. This program should accompany the addition of HIV to the list of reportable communicable diseases, along with the necessary allocation of public health resources at the regional level to undertake the index case and partner counseling processes.

Recommendations

1. HIV should be added to the list of reportable conditions in Schedule A of the Health Act Communicable Disease Regulation.

2. A non-nominal option should be available for persons being voluntarily tested who do not wish their names to be reported to the public health authority.

3. Physicians, other health professionals, and all persons likely to view HIV test results should be informed of their duty under the *Health Act* to maintain confidentiality around the information contained in such reports.

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5. Adequate resources must be available for patient counseling and partner notification, counseling, and follow up.

6. Best practices protocols for enhanced partner notification should be developed and disseminated, and the process of public health partner notification should be subjected to continuous quality control.

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7. Regional public health nurse contacts physician to discuss case and offer assistance with contact naming. Public health nurse contacts patient if permitted; otherwise, takes contact names from physician. Public health nurse does partner follow up.

8. B.C. Centre for Disease Control continues to compile aggregate statistics, informed by enhanced local epidemiological follow up. Local health authorities compile regional statistics.

PART TWO

Informed Consent, Confidentiality, and Partner Notification: Best Practices

The community consultation process has demonstrated many of the HIV/AIDS related concerns of residents of British Columbia. These pertain to issues about informed consent to HIV testing and treatment, the confidentiality of people living with/at risk for HIV/AIDS, and the complex controversies around partner notification.

In response to these concerns, the rest of this report will make an effort to highlight best practices regarding these issues. It is the expectation that informed consent is attained in a manner that is consistent with the standards of the highest quality of practice, that patient confidentiality be maintained according to legal and ethical standards, and that partner notification programs be consistent with the current evidence. An evaluation of each of these should be included in the overall evaluation of making HIV reportable. The following is the minimum that is expected of health care professionals in British Columbia.

Informed Consent to HIV Testing

In the absence of an emergency, informed consent is required before any medical procedure, including HIV-testing, can be performed on a patient. The goals of the informed consent requirement are two-fold: first, it imposes responsibilities on health care professionals, and second, it imparts autonomy rights to patients.

The responsibilities of the professional are to recommend procedures that are in the best interests of the patient. In order to make this determination, the professional must disclose adequate information, ensure that the patient's consent is voluntary, make certain that the patient is mentally competent to make decisions, and be sure that the patient has the legal capacity to provide a valid consent. The patient then has the right to exercise his or her autonomy by either consenting or refusing to consent to the recommended procedure or testing.

Disclosure of adequate information requires that the health care professional disclose the amount of information that a reasonable person in that patient's situation would find relevant.[13] At a minimum this should include information about potential risks, benefits, alternatives, and what could happen if the patient refuses treatment or testing. In addition, HIV testing should be accompanied by pre- and post-test counseling and performed in accordance with national best practices.[14,15]

It is also necessary to have a discussion about confidentiality, particularly the limits to confidentiality and circumstances where the professional would release information with or without the patient's permission. Care should be taken to ensure that the patient understands that he or she has a choice of being tested nominally or non-nominally, and what that means. It should also be made clear that regardless of the testing option, a positive test result will prompt important discussions about partner notification.

Confidentiality

Health care professionals are obligated to treat information about their patients as confidential. This means that, except for rare occasions, the health care professional cannot disclose information without the patient's permission. This includes information about an individual's HIV status.

Most information collected by health care professionals is confidential because it originates out of a promise of confidence, which is necessary for the functioning of the therapeutic relationship.[16] It is often necessary for health care professionals to know intimate details about individual patients. It is only because of the promise of "confidence" or the promise to keep it "a secret" that a patient would reveal this information in the first place. Therefore, the promise of confidentiality is fundamental to most relationships between health care professionals and patients.

Confidentiality is also important for another reason, namely, respect for the principle of patient autonomy.[17] A mentally competent patient with the legal capacity to make decisions is autonomous in the sense that he or she can decide what should happen to his or her own body. A necessary extension of this is that a patient also has the right to determine when and how confidential information is to be used or disclosed.

Exceptions to Confidentiality

A patient's right to confidentiality is not absolute. Under certain conditions the professional may disclose, or be legally required to disclose, confidential information. This is generally known as the "duty to warn." The health care professional will have a duty to warn if, on the balance of probabilities, the following conditions are satisfied: the patient poses a clear risk to an identifiable person or group of persons, if there is a risk of serious bodily harm or death, and/or if the danger is imminent.[18]

Once the decision is made to disclose this information, the professional must first inform the patient that unauthorized disclosure will occur and allow the patient the opportunity to disclose voluntarily. If the patient will not comply, the professional should disclose minimal information sufficient to prevent the expected harm and disclose only to those who have the ability to prevent the harm from occurring. The relevance of this to HIV is stated in the Canadian Medical Association's 1996-policy statement on AIDS:

> Disclosure to a spouse or current sexual partner may not be unethical and, indeed, may be indicated when physicians are confronted with an HIV-infected patient who is unwilling to inform the person at risk. Such disclosure may be justified when all of the following conditions are met: the partner is at risk of infection with HIV and has no other reasonable means of knowing the risk; the patient has refused to inform his or her sexual partner; the patient has refused an offer of assistance by the physician to do so on the patient's behalf; and the physician has informed the patient of his or her intention to disclose the information to the partner.[19]

The duty to warn is often confused with the public health practice of "partner notification;" however, the two are fundamentally different.[20] As previously discussed, the duty to warn occurs when the health care professional has reason to believe that the patient is going to expose an identified partner to a significant risk of acquiring HIV without revealing his or her HIV infection. The duty to warn is not a voluntary activity, and when it is done it is not possible to protect the index patient's anonymity. However, partner notification is purely voluntary and always anonymous.

Partner Notification

Partner notification is the voluntary and anonymous public health activity of telling the partners of an "index patient" that they have been exposed to HIV. An index patient is someone who is diagnosed with HIV or AIDS. Partners are persons with whom the index patient has had unprotected sex, shared injecting equipment (needles, rigs), or engaged in some other high-risk activity. Partner notification is a purely voluntary activity. The index patient does not have to give out his or her partner's identity and is in control of the information he or she chooses to disclose to public health professionals. Partner notification is anonymous because after the index patient chooses to disclose his or her partners' contact information, the index patient's identity is not revealed to the partner(s) under any circumstances.

The literature pertaining to partner notification and HIV provides compelling evidence that notifying partners of patients newly diagnosed with HIV/AIDS is an ethical duty that is important to fulfill (Appendix E). Partner notification provides important information to identified contacts and enhances the ability of public health professionals to contain the spread of HIV in the general population.

There are three basic methods of partner notification: patient referral, provider referral, and conditional referral.

Patient referral is when the index patient decides to tell his or her partners that they have been exposed to HIV. If this method is chosen, public health professionals will counsel the index patient about how to approach partners, what to tell them, and where to refer them for services (testing, counseling, and treatment, if needed).

Provider referral is when the index patient gives the public health professional the names and locating information of his or her partners. The public health professional (provider) will then contact the partners, tell them of their potential exposure, and refer them to services. In all circumstances the provider will protect the anonymity of the index patient.

Conditional referral is a combination of patient and provider referral. The index patient chooses to notify partners him or herself, but makes an agreement with the public health professional that if he or she cannot locate any or some partners, or if some or any of those partners do not report to public health for follow up, the provider will contact them directly.

What are the benefits of partner notification?

There are a number of good reasons for partner notification. For instance, partner notification can identify partners who have been infected with HIV, but who are unaware of their infection.[21,22,23,24,25,26,27,28,29,30,31,32,33,34,35] The partners of index patients (people newly diagnosed with HIV) are at extremely high risk for having contracted HIV. In fact, some studies have revealed that the prevalence of HIV among partners of index patients could range from 15 per cent to over 30 per cent.[23,36] One study published in the *Lancet*[23] revealed that out of 350 named contacts (partners) who received HIV testing and counseling 53 (15 per cent) were HIV-positive and previously unaware of their status. Another more recent study presented to the *XI International Conference on AIDS* (1996)[30] explained that out of 560 contacts who received HIV counseling and testing, 122 (22 per cent) were HIV-positive and were previously unaware of their HIV-positive status. This suggests that partners of index patients are at high risk of contracting and spreading HIV.

Another benefit of partner notification is that it can help modify the high-risk behaviours of partners who may not be infected but were unaware of their exposure to HIV.[37,38,39] A study presented to the *Fourth Conference on Retrovirus and Opportunistic Infections* (1997)[38] explained that in a randomized controlled trial, condom use was significantly higher and the number of new sexual partners was fewer in the group of sexual partners that received enhanced HIV counseling and education than in the control group who did not receive this enhanced intervention. An international study conducted in Zaire found that discordant couples who were offered intensive counseling resulted in substantially increased condom use, from less than 5 per cent at baseline to 71 per cent at 1-month follow-up, and 77 per cent at 18-month follow-up.[39]

There is also evidence to suggest that most partners who are told about their exposure to HIV are appreciative of this information.[40] A 1990 U.S. study, published in *JAMA*, revealed that of 132 partners located, 87 stated that the health department did the right thing by telling them about their exposure, and 92 per cent said that the health department should continue with this valuable activity.

It is also possible to make some loose generalizations about the efficacy of the different models of partner notification. Most of the literature suggests that provider referral is much more effective in contacting partners and revealing undiagnosed HIV than patient or conditional referral.[25,26,27,41] A study published in *The New England Journal of Medicine*[26] compared the results of provider referral and patient referral. In the provider referral group 78 of 157 partners (50 per cent) were successfully notified, whereas in the patient referral group 10 of 153 (7 per cent) were notified. It was further found that of the partners notified through the provider referral group, 94 per cent were unaware that they had been exposed to HIV.

Another important finding is that, in general, most index patients are willing to participate in partner notification programs if their anonymity can be guaranteed.[42] A study of 25 HIV-positive women in the U.S. revealed that 68 per cent of the participants were willing to give the names of their partners, as long as the index patient's confidentiality was maintained. Interestingly, however, 20 per cent were willing to participate in a partner notification program even if their names were disclosed to the partner.

What are the problems with partner notification?

There are a number of limitations associated with partner notification as well. For instance, the ability to notify partners of index patients is only as good as the contact information the index patient can or will disclose.[8,22,41,43] The index patient may not be able to identify a particular partner because of an anonymous encounter where high-risk behaviour took place, or perhaps the index patient simply does not want to disclose this information at all. Since partner notification requires the voluntary participation of the index patient, there is no way to get around this limitation. Furthermore, the index patient's refusal to participate in partner notification should in no way limit his or her ability to access services he or she receives from the health care providers.

Patient referral is very cost-effective, but since it requires the index patient him or herself to initiate contact with past partners, the index patient's anonymity is necessarily compromised.[44] Although this method of partner notification is the index patient's choice, there is often a concern about the vulnerability of the index patient to emotional or physical harm.[45,46] For some partners, their only possible exposure to HIV may be the index patient, so it will allow that partner to identify who put him or her at risk of infection. Domestic violence screening must be part of post-test counseling before any form of partner notification can be initiated.

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Appendix A
Health Officers Council - October 20, 1999
Discussion Paper - HIV Reportability

Submitted by: Dr. Patricia Daly and Dr. Rob Parker on behalf of the Administrative Council of Lower Mainland Medical Health Officers

Issue:

Whether or not HIV infection should be added to the list of reportable diseases under Schedule A of the C.D. Regulations of the Health Act.

Background:

HIV infection is currently not reportable in BC, while AIDS is a reportable disease (although usually reported by initials only). Periodically the Provincial Communicable Disease Policy Committee has considered whether or not HIV infection should be added to the list of reportable diseases. To date, this recommendation has not been made. In September 1999, the Administrative Council of Lower Mainland Medical Health Officers referred the question of HIV reportability to the Provincial CD Policy Committee, with the recommendation that a discussion paper be developed and circulated to Medical Health Officers and others for further consideration.

There are several reasons why the Administrative Council has reconsidered this issue, and these can be divided into three groups: Surveillance and epidemiology considerations, public health considerations, and case management considerations.

1. Surveillance and Epidemiology Considerations

The epidemiology of HIV in BC is monitored through non-nominal data provided by the Provincial Laboratory to the Division of STD/AIDS Control at BCCDC. Demographic and risk factor information is available, although not on all cases. Region of residence of HIV cases is generally not available - for the purposes of surveillance, newly diagnosed cases are assigned to the region of testing (based on the practitioner submitting the test) rather than the region of residence of the case.

Based on BCCDC data, there has been a change in the epidemiology of newly reported HIV cases in recent years. While MSM were the predominant risk group until about 1994, IDUs have predominated in the last 5 years. The outbreak in IDUs appeared to peak in 1996, and has been on the decrease since that time as this population becomes saturated. Infections among heterosexuals have been increasing, and BCCDC anticipates that the number of new infections in non-IDU heterosexuals will surpass those in MSM this year. Unfortunately, it is unclear whether or not the increase in

heterosexuals is due to increased testing or a true increase in the rate of new infections.

The changing epidemiology of HIV has prompted initiatives in the Lower Mainland (and other health regions).

Recently:

- The Ministry of Health has asked all regions to develop HIV Action plans;
- Several regions are considering or implementing new or expanded HIV control initiatives.

Questions:

Are the currently available HIV epidemiological data sufficient for regions to develop plans now and in the future, and to evaluate HIV control programmes?

If the answer is no, would making HIV infection reportable facilitate or hinder the collection and quality of epidemiological data?

2. Public Health Considerations

Contact tracing following HIV diagnosis in BC is currently the responsibility of the infected individual, with the assistance of their physician or the practitioner who has ordered the test. Public health has played little role in contact tracing, although nurses in the Division of STD/AIDS Control at BCCDC telephone physicians of all newly diagnosed cases of HIV and offer their assistance in contact tracing.

According to current HIV testing and counselling guidelines, patients undergoing HIV testing are counselled that they must return in person for test results (i.e. results are not to be given out over the phone). However, some positive test results are left unclaimed. These unclaimed results may have significant public health implications e.g. pregnant women known to be positive who do not return for results, and who therefore do not access antiretroviral therapy.

Recently:

- In a high-profile criminal case involving an HIV-positive individual who had unprotected sex with several contacts, the judge recommended that such situations should be dealt with using the Health Act (i.e. through the MHO);
- STD/AIDS Control and Medical Health Officers have been made aware of cases of HIV where contact tracing has been inadequate and contacts are unknowingly being placed at risk - these cases sometimes involve contacts who are mentally ill and unable to protect themselves, or women in potentially violent relationships;

- STD/AIDS Control reports very few practitioners make use of the offer to assist in contact tracing;
- Recognizing the problems in the current practices of contact tracing, STD/AIDS Control has proposed a programme for more active public health involvement in contact tracing;
- Data are available which demonstrate the effectiveness of antiretroviral therapy in preventing HIV transmission from a positive mother to her child during pregnancy.

Questions:

Are MHOs (and other public health staff) willing to become more involved in contact tracing for HIV cases?

If so, would making HIV reportable facilitate or hinder contact tracing and other public health activities?

3. Case Management Considerations

Before the availability of effective treatments for HIV infection, there was very little that could be offered to newly diagnosed HIV cases that would have any impact on mortality, and therefore there appeared to be little benefit to the infected individual from reporting infections to public health.

Recently:
- Antiretroviral medications that can significantly prolong life and reduce morbidity are now available;
- There is good evidence to support beginning these as early as possible in the course of infection;

Public health has a tradition of assisting individuals who have communicable diseases (e.g. TB) in ensuring access to and compliance with the best available treatment, both to improve the health of the infected person and reduce the risk of infection to contacts. Many persons infected with HIV are from marginalized groups (e.g. IDUs, First Nations) who do not have the same access to antiretroviral therapy as others. Antiretroviral therapy, taken appropriately, will reduce viral load, which will benefit the infected individual and could reduce the risk of transmission to others. The BC Centre for Excellence in HIV/AIDS is studying simplified antiretroviral treatment regimens (delivered with public health assistance, like directly observed or assisted therapy for TB) that could be considered for those with disorganized lives.

Questions:

Would making HIV reportable facilitate or hinder the accessibility of early antiretroviral treatment of cases?

Potential Problems with Reportability

HIV infection is currently reportable in some provinces (and US States) but not others. Based on the experience in other jurisdictions and issues raised by local community groups, the potential "risks" of making HIV reportable must be considered along with the potential "benefits". These are considered in Tables appended to the discussion paper. To summarize the concerns regarding reportability:

Many experts believe that making HIV reportable will discourage some people from getting tested, because of confidentiality concerns (and there is some limited evidence to support this);

- Some community groups, particularly among the MSM community, strongly oppose making HIV reportable.

In addition, if HIV is made reportable, this will have resource implications for public health involving:

a) Contact tracing;
b) Follow-up of new cases to collect epidemiological information;
c) Tracking down "positives" who do not collect their results;
d) Notification of the Canadian Blood Agency if donation/transfusion is a concern;
e) Counselling of new cases and referral to "best possible treatment" programs;
f) Public health participation in special treatment programs;
g) Names may dictate that MHOs use the Health Act more regularly in dealing with difficult cases

In addition to the above, the issue of anonymous test sites must be considered. In most jurisdictions where HIV is reportable, anonymous test sites are available for those individuals who wish to undergo anonymous testing. The resources required to establish such sites in BC, as well as the impact of anonymous testing on the ability to monitor the epidemiology of HIV, are uncertain. This will depend on the number of people who will choose to be tested anonymously.

Tables 1-3 (appended) outline the issues to be considered under the three headings of "Surveillance and Epidemiology", "Public Health Considerations" and "Case Management". These will facilitate discussion and allow members of Health Officers Council to answer the questions under consideration.

After considering each of these questions, members will be asked to vote on a resolution concerning HIV reportability.

Table 1 - Surveillance and Epidemiology

HIV Reportable	HIV Not Reportable
• May discourage testing in some persons, particularly among certain high risk groups - this may adversely affect the ability to collect surveillance data and monitor trends	• Less concern about confidentiality of results may facilitate testing, particularly among certain risk groups, improving surveillance
• If anonymous testing is available and many choose this option, it may affect the ability to monitor epidemiology	
• Allows public health follow-up of reported cases to fill in gaps in current epidemiology, particularly region of residence and risk factor information	• Currently region of residence and risk factor information on many cases is missing
• May provide better risk factor information for monitoring the epidemic and assessing control efforts	• Determining incidence depends on ability of laboratory to identify serial test results of individuals using non-nominal data
• May allow better information on incidence of HIV infection among risk groups	• Removal of duplicates done by BCCDC but may not be complete
• With identifying information, easier to reduce duplicate reports	• Epidemiological information collected and collated by BCCDC
• Will require commitment of public health resources at the regional level to follow-up and collect epidemiological data on cases	

Will making HIV reportable facilitate or hinder the collection and quality of epidemiological data?

Table 2 - Public Health Considerations

HIV Reportable	HIV Not Reportable
• Public health can participate in the identification, notification and counselling of contacts • Empowers MHOs to use the Health Act to deal with difficult cases e.g. cases who are deliberating exposing others to HIV • May allow public health to follow-up unclaimed positive HIV results (although only if sufficient contact information is available) • Ensures direct notification of the Canadian Blood Agency for HIV cases where donation or receipt of blood products or organs is an issue	• Public health participation in contact tracing is more complex - current pilot initiative proposed by BCCDC • Use of the Health Act may still be possible in some instances, but is more difficult • Patients with unclaimed positive test results are usually not contacted • Notification of the Canadian Blood Agency is the responsibility of the testing physician - BCCDC nurses currently remind testing physicians of this responsibility through telephone follow-up

Would making HIV reportable facilitate or hinder contact tracing and other public health activities?

Table 3 - Case Management Considerations

HIV Reportable	HIV Not Reportable
• All reported cases can be counselled and directed to the best possible treatment programmes by public health as early as possible • Empowers public health to participate in special treatment programmes e.g. Maximally-assisted therapy, treatment of pregnant women, screening and early treatment of high risk groups • If confidentiality concerns discourage testing, infected persons may not be aware of their infection in the early stages and would not access treatment as soon as they might otherwise	• Counselling and initiation of treatment of cases is the responsibility of the testing physician • Less concern about confidentiality may, in some instances, result in early treatment of infected persons

Would making HIV reportable facilitate or hinder early antiretroviral treatment of cases?

Appendix B
Written Submissions

Written submissions were received from the following individuals and organizations:

College of Physicians and Surgeons of British Columbia
HIV Reporting
College Position Paper, March 2000

British Columbia Persons with AIDS Society
Letters to Dr. Perry Kendall, May 24, 2000 and January 25, 2001

Minister's Advisory Council on Women's Health
Letter to Dr. Perry Kendall, June 26, 2000

R. Paul Kerston
CHC-2, Vancouver/Richmond Health Board
Letter to Dr. Perry Kendall, June 26, 2000

Dr. Linda Poffenroth
Deputy Medical Health Officer
Capital Health Region
Correspondence to Dr. Perry Kendall, June 28, 2000

Ministry of Health HIV/AIDS Advisory Committee
Letter to Dr. Perry Kendall, July 4, 2000

Minister's HIV/AIDS Advisory Committee
Issue: HIV Reportability
1999/2000 Annual Report Minister's HIV/AIDS Advisory Committee

Patricia Rodney, RN, MSN, PhD
Assistant Professor
University of Victoria School of Nursing
Faculty Associate, UBC Centre for Applied Ethics
Research Associate, Providence Health Care Ethics Services
Letter to Dr. Perry Kendall, July 5, 2001

YouthCO AIDS Society
Letter to Dr. Perry Kendall, August 21, 2000

General Assembly of the Pacific AIDS Network
Letter to Dr. Perry Kendall, October 1, 2001

CIAL HEALTH OFFICER
MAY 0 3 2000
VICTORIA, B.C.

COLLEGE OF PHYSICIANS & SURGEONS OF BRITISH COLUMBIA

April 12, 2000

PERSONAL AND CONFIDENTIAL

Dr. Perry Kendall
The Prov. Health Officer
Rm. 3002 - 1810 Blanshard St.
Victoria, B.C.
V8V 1X4

Dear Dr. Kendall:

At the most recent meeting of the Council of the College of Physicians and Surgeons of British Columbia, the attached position paper was adopted in support of implementation of nominal HIV reportability in British Columbia.

The policy is submitted at the direction of Council for your consideration.

Yours sincerely,

T. Peter Seland, MD, FRCPC
Deputy Registrar

TPS/lb

cc: Dr. T.F. Handley

1807 WEST 10TH AVENUE, VANCOUVER, B.C. V6J 2A9 1-800-461-3008 TEL. (604) 733-7758 FAX (604) 733-3503

HIV REPORTING

College Position Paper
March 2000

HIV infection is currently not reportable in BC, while AIDS is a reportable disease (although usually reported by initials only). The College of Physicians and Surgeons of British Columbia recommends that HIV infection be added to the list of reportable diseases under Schedule A of the Communicable Disease Regulations of the Health Act.

The College recognizes that currently the BCCDCS provides an enhanced non-nominal HIV surveillance system yielding some of the best epidemiological data in Canada, data that is better than that in many provinces where HIV is reportable. The centre's staff follow up directly with every doctor submitting a positive HIV test to offer assistance with contact tracing and patient care (including facilitation of access to anti-retroviral drugs).

The College recognizes further that the introduction of home-based HIV testing has the potential to divert public health access and tracking of HIV positivity.

It notes, as well, that compulsory HIV reporting does not prevent prenatal transmission of HIV as that does vary with the numbers of expectant mothers agreeing to screening and subsequently to prophylactic treatment or final termination. It is noted, as-well, that making HIV reportable might lead to more prenatal transmission by deterring pregnant females from seeking prenatal care.

Notwithstanding the above, it is noted as well that:

- Surveillance remains incomplete and epidemiology is changing

Demographic and risk factor information is not available on all patients. Regions of residence of new cases are unknown, as assignment is by region of testing. The shifting predominance of populations at risk from MSM through IDU and onto an emphasis of non-IDU heterosexual new cases raises particular concerns.

- There are reported instances of contact tracing being inadequate so that contacts (including especially the mentally ill and women in potentially violent relationships) are unknowingly being put at risk.
- Antiretroviral therapy is now effective in preventing HIV transmission from a positive mother to her child during pregnancy.
- Antiretroviral medications that can significantly prolong life and reduce morbidity are now available and early implementation adds extra benefit.

.../2

As has been noted by Dr. Patricia Daly, MOH, Public Health has a tradition of assisting individuals who have communicable diseases in ensuring access to and compliance with the best available treatment, both to improve the health of the infected person and reduce the risk of infection to contacts. Many persons infected with HIV are from marginalized groups (e.g. IDU's, First Nations) who do not have the same access to antiretroviral therapy as others. Antiretroviral therapy, taken appropriately, will reduce viral load, which will benefit the infected individual and could reduce the risk of transmission to others. Simplified antiretroviral treatment regimens are being studied that could be considered for those with disorganized lives.

The College recognizes that implementation of nominal HIV reportability has significant resource implications and is confident that those can be properly addressed in that implementation.

T. Peter Seland, MD, FRCPC
Deputy Registrar
TPS/lb

BRITISH COLUMBIA
PERSONS WITH AIDS
SOCIETY

Dr. Perry Kendall
Provincial Health Officer
BC Ministry of Health
Government of British Columbia

May 24, 2000

Dear Dr. Kendall,

I am writing to you on behalf of the BC Persons with AIDS Society to express our opposition to the proposal by the regional Medical Officers of Health to institute nominal HIV testing in this province.

The BC Persons with AIDS is Western Canada's largest AIDS organization, with over 3200 HIV+ members. Our mandate is to empower people living with HIV disease and AIDS through mutual support and collective action.

We are strongly opposed to the nominal testing proposal for two primary reasons.

1) It will dramatically discourage and dissuade people from getting tested for HIV, particularly those people who are marginalized or vulnerable in our society, such as women (particularly women of ethnic minorities), and youth.

2) Nominal testing would lead to decreased physical and emotional safety for those people who test positive. HIV remains today associated with major stigmas and discrimination. People living with HIV/AIDS are frequently physically attacked and socially isolated as a result of their serostatus, and nominal testing and partner notification will escalate these problems.

We have been told that one of the justifications for this proposal is to be able to collect better epidemiological data. We see no reason why this data could not be collected without the use of people's names. Furthermore, it is unacceptable that people's lives be placed in jeapordy in the name of data collection.

Please feel free to contact me should you wish to discuss these issues further.

Yours sincerely,

Glen Hillson
Chair
BC Persons with AIDS Society

Pacific AIDS Resource Centre
1107 Seymour Street
Vancouver, B.C.
V6B 5S8

Tel.
(604) 681-2122
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(604) 893-2251
e-mail: bcpwa@parc.org

Registered non-profit society Reg. #0760124-11-27

A member of

Minister's Advisory Council on Women's Health
5th floor, 1515 Blanshard Street • Victoria, British Columbia • V8W 3C8

Date: June 26, 2000

To: Dr. Perry Kendall, B.C. Provincial Health Officer
3002-1810 Blanshard St
Victoria BC V8V 1X4

From: MACWH

Re: HIV Reportability Discussion Paper
MACWH

Thank you for attending our meeting on June 11,2000 to discuss this issue. As you explained, the Health Officers' Council of B.C. has recommended adding HIV infection to the list of reportable diseases in the Health Act Regulations. The reasons given for the recommendation and our comments about each one follow:

Reason 1: Surveillance would be improved, facilitating improved tracking of the epidemic and presumably better and more timely allocation of appropriate resources.

Comments:

The main argument under this section appears to be that nominal reporting of test results would link population testing results to addresses of patients instead of physicians, thereby providing a more accurate description of the distribution of infections across the province. Could this result be achieved by developing a mechanism under the current system to ensure that patient's address is recorded?

Presumably it is also assumed that reportability would reveal more people with HIV infection by facilitating contact tracing. However, confidentiality remains a key issue with respect to HIV infection. Some communities in BC, for example aboriginal communities, are extremely small and confidentiality is virtually impossible to maintain. It would be key to work out with people in these communities exactly how a reported HIV infection would be investigated. Our point here is that HIV reportability may act as a deterrent for testing if there is not a very strong belief that confidentiality can be protected. In the B.C. Women's Aboriginal Health Pap smear outreach clinics, for example, staff are frequently told by community women that they prefer to have the test done by outside examiners because they do not believe there is confidentiality within their local health care setting.

The discussion under this section also seems to imply that a reporting system would result in a better estimate of the "true increase" in the rate of new infections. This would be impossible, of course, in the absence of universal testing.

...2

Reason 2: Contact tracing would become the responsibility of the skilled public health system, reducing the number of unclaimed test results and ensuring that infected individuals are aware of their infection and can seek treatment.

A number of examples are used in this section to point out the possible benefits of reportability: One of these is of a pregnant woman who does not claim a test result thereby putting her infant at risk. As we all know, there has been a concerted effort in B.C. for many years to ensure that all pregnant women are offered testing. There hasn't been an infant born with (or diagnosed later with) HIV in B.C. for many years, so it seems unlikely that the current system is missing cases. It's also pointed out in this section that ART can prevent vertical transmission. That's true, but taking ART remains and should always remain the woman's choice.

Another reason cited here is the potential for using the Health Act to restrain (infected) individuals from engaging in high-risk activities. This is very problematic. If a person is knowingly transmitting infection, then the criminal code is likely to offer a better remedy. Where would a person be confined under the Health Act and for how long? How can we possibly know if a person under Health Act order is complying?

It will take more than public health's awareness of risk and a medical health officer's order to protect vulnerable individuals such as women in violent relationships. MAC is concerned that notification of a woman by a public health worker, and the necessary subsequent communications involving the spouse, may well be a trigger for additional violence within the relationship. Notification of male partners of positive women may also result in very real risk of violent reprisal.

In B.C, the Health Act has been used to target individuals. The highest profile of these cases have involved women working in the sex trade in certain communities, and the effect of the orders ultimately was that the women fled the jurisdiction. Who exactly would the health officer target for intervention? We would be very concerned about the potential to use this legislation to restrain the most marginalized, especially women. HIV infection is certainly spread through individual contacts. However, it is an infection that is profoundly potentiated by social conditions. The risk is not so much from individuals as it is from "deadly public policies" which result in crowded, unsafe housing conditions, a black market in illicit drugs, and the abandonment of persons with psychiatric illnesses.

Reason 3: Health officials have an obligation to ensure that people with HIV infection have an opportunity to access the effective treatments which now exist.

...3

Certainly detecting a previously undiagnosed infection will provide a new opportunity for counselling and treatment. However, it seems that the arguments used in this section, i.e. the need to ensure access for the most marginalized and the development of new approaches to do this has nothing whatever to do with reportability. We already know the risk for most of those individuals, and it is likely that they will (or should) have been offered testing in any case if they have contact with the primary care system. Again, the issue here is whether reportability will add an element of perceived coercion which to the already complicated environment in which outreach is done.

Yours truly,

Marcia Hills

Marcia Hills
Chair

P.O. Box # 4923
Vancouver, B.C. V6B 4A6

26 June 2000

SENT VIA E-MAIL

Dr. Perry Kendall
Provincial Health Officer,
Province of British Columbia
Ministry of Health
Room 3002 – 1810 Blanshard Street
Victoria, B.C. V8V 1X4

Re: HIV Reportability

Dear Dr. Kendall:

As the member chosen (by CHC-2 of the V/RHB) to attend your meeting with V.A.N.D.U. on Saturday, June 24th, I wish to express my/our very deep thanks for coming, for allowing me to attend and for speaking with me both during and after the meeting.

I feel that your bottom line on this issue will be some attempt to balance anticipated positive outcomes against anticipated negative ones. In *my* mind (and in the minds of many others, I am sure) there are more potential negative than positive outcomes. As discussed at the V.A.N.D.U. meeting, the statistics may appear to show that more contacts are being provided with named positive results (compared with anonymous) but you may never know if more individuals are even being tested in the first place – as a result – or, more likely, fewer. If ten people come forward for anonymous tests – and all test positive – and then, each person names five more people whom they suggest for tests as well (through contact tracing) you will have performed 60 tests. However, if only six people come forward at the beginning (due to fear of being named upon result) then your numbers are already reduced. Naming will not increase *those* numbers and that is what the goal is. Perhaps through naming, it appears that more contacts are provided (statistically) but this connection seems rather tenuous to me. Overall, numbers would appear to be *reduced* through reportability.

As it stands now, the onus is on individuals to provide tracing information. Nothing in these proposed changes will alter that. Thus, the net benefit remains negative.

Being one of the last of a group of jurisdictions to join in this experiment (approximately 48 out of 60 state/provincial jurisdictions, to date, have reportability) does not provide justification for British Columbians not thinking for ourselves.

Not only physicians are seeking ways to stop the spread of this insidious disease. Surely a lack of contact with infected persons *will* stop it. Thus (and obviously) it is the finding of those infected which is our task. Taking names will not actually help this in any way. In fact, *if HIV positive tests were reportable, I, for one, would never have come forward and discovered my infection within only months.* I was probably infected in another jurisdiction (California). In this age of travel, contact tracing can only go so far…

…/2

Our goal is to bring people to treatment/counselling and to prevent transmission as much as possible. Naming will not do that. If just one individual could be provided timely treatment/counselling as a result of contact tracing (and who might otherwise not have known s/he was infected) we *might* be tempted to say that the risks are outweighed by the benefits of this new procedure. However, if fewer people are coming for tests, then the spread of the disease – which is our ultimate concern, here – is really *not* being stopped.

Finally, as discussed on Saturday, the harm inherent in naming an infected person has serious social and even physical repercussions – harm that cannot be undone. When Ministry records can truly be guaranteed as confidential (and when incidents such as private health records being found in Ontario, as happened not long ago, do not happen) such harm will be reduced – but that harm will still be potentially present!

To specifically address the issues you raised in this meeting, I would suggest that alternatives be considered *ahead of any requirements for reportability*:

- **Workshops and/or bulletins in regular mailings for physicians on the subject of contact tracing, with suggestions on methods.**
- **New funding for C.D.C. positions (or secondments, in the interim) to provide province-wide support for these doctors to assist with techniques or person-hours, where useful.**
- **Statistics be recorded and compared with present methods, as is being done elsewhere with reportable results.**
- **Criminal complaints against individuals may proceed with names when an infected individual is wantonly spreading the infection without concern. *Prior* naming is not a solution, here.**

All of this, and/or other ideas, should be explored prior to any implementation of HIV reportability. Thus, I urge you to write a report that informs authorities, in short, that while physicians are seeking reportability, and there is some support for the measure, such support is largely only within the medical community and does not include social considerations. What we all want done will not be done with this method. Many individuals who are and would be affected are adamantly against the idea because *it will not do things it should, and it will do things it shouldn't!*

Sincerely,

//s//

R. Paul Kerston
(604) 309-4282 (+ 9633 for messages)
e-mail: rpaul@vcn.bc.ca

Subject: HIV reportability
Date: Wed, 28 Jun 2000 08:30:47 -0700
From: "Poffenroth, Linda" <Linda.Poffenroth@caphealth.org>
To: "'perry.kendall@moh.hnet.bc.ca'" <perry.kendall@moh.hnet.bc.ca>

Perry, thanks for the opportunity to participate in the teleconference yesterday - it was quite illuminating. I think that many of the comments highlighted the concerns in the community about the effect that lack of resources is having on our ability to deal with HIV infection and AIDS, and our need to understand the positive and negative consequences of nominal testing for HIV infection. Along those lines, I do have a bit more information which I neglected to share yesterday.
PEERS (the Prostitutes Empowerment, Education and Resource Society) has almost completed a major interview survey of sex trade workers in Victoria. They have interviewed almost 100 off street sex trade workers (a first, as far as I know), will interview 50 on street sex trade workers and 50 who have exited the trade. The research team (I am a member) has done a preliminary analysis of some of the data, and it is clear that the vast majority of STWs are working for economic reasons - they cannot live and support their children on welfare. This means that they cannot afford condoms, either and they report that free ones are hard to access. Although the reported rate of HIV infection is low, over 30% (in this first look) say they have hep C, so I think that drug use has been an issue for many. The majority also report that they do not have a regular doctor. Based on this preliminary data, as far as harm reduction is concerned, we need to do something about access to condoms and to health care for the STWs. As far as reportability is concerned, these women would not be tested for HIV infection if they thought that their name would be known to anyone in authority, since this might risk a visit from MCF. It might also result in their being unable to work in the sex trade, in the absence of other sources of income. This is not a small problem here since PEERS estimates that there are 2500-3000 STWs. Our best hope is to build on the positive relationship the STWs have with the street nurses and PEERS and try to deal with their barriers to HIV/AIDS care. I really do not see how nominal testing for HIV infection would be of benefit. Even if we give people the option of anonymous testing (most of the testing done here by the street nurses is anonymous), they are in such a high risk situation and have so little control over the risks they take that they may just choose not to be tested.

Just a few thoughts. I am sure you will hear more from the Positive Women's Network.

Linda

July 4, 2000

Dr. Perry Kendall
Provincial Health Officer
Ministry of Health and Ministry
Responsible for Seniors
3rd Flr, 1810 Blanshard St
Victoria BC V8V 1X4

Dear Dr. Perry Kendall:

Thank you for your presentation to the May 25, 2000 Ministry of Health HIV/AIDS Advisory Committee meeting on the proposal that HIV be declared a reportable condition in British Columbia.

Further to our letter of June 15, 2000 to the Minister of Health, the Honourable Mike Farnworth, individual members commented on the following issues during the HIV/AIDS Advisory Committee meeting:

- parameters for community consultation regarding the proposal that HIV be reportable;
- the need for consultation with individuals and agencies outside the Lower Mainland, including, through the Pacific AIDS Network, rural communities;
- the inclusion of marginalized individuals in the consultation;
- if HIV is a reportable condition, the effect of stigma and the potential for violence on marginalized groups' willingness to seek testing;
- increasing community education to encourage non-nominal testing;
- experiences in other jurisdictions with regard to reportability's effects on partner tracing and individuals' willingness to seek testing;
- inconsistent evidence regarding early treatment of HIV;
- funding and resource implications of reportability;
- that reportability may create a false sense of security among non-positive people; and
- opportunities for evaluating the effectiveness of reportability, if adopted.

We trust these points will assist you in your discussions with HIV/AIDS stakeholders regarding HIV reportability. Please feel free to contact us if you would like to further discuss the committee's deliberations.

Sincerely,

Joan Bray.

Joan Bray
Co-chair
HIV/AIDS Advisory Committee

p.c. Honourable Mike Farnworth
Minister

Andrew Hazlewood
Assistant Deputy Minister
Regional Programs Policy

Dr. Michael Rekart
Director
British Columbia Centre for Disease Control Society

Elena Kanigan
Director
HIV/AIDS Division

Confidentiality

Issue: HIV Reportability

The Minister's HIV/AIDS Advisory Committee has advised the Minister to postpone a decision on a Medical Health Officers' proposal to make HIV reportable. While the committee is aware of the need for public health officials to have accurate information about HIV, the committee cannot support the current proposal. The committee has yet to hear compelling arguments for making HIV reportable. Reportability also has wide-ranging implications. Breaches of confidentiality carry the risk of violence towards HIV-positive people, discrimination by employers and refusal to undergo treatment for fear of disclosure. The committee believes there may be other options for achieving the same result that have fewer consequences for people living with HIV/AIDS.

Options are needed to:

- improve notification of partners of HIV-positive people;
- control the spread of HIV and co-existing diseases, such as sexually transmitted diseases or Hepatitis C;
- assist in HIV/STD prevention planning and encourage early care; and
- improve understanding of local HIV epidemiology.

Issue: HIV Drugs on Pharmanet

Pharmacare and the College of Pharmacists have proposed including HIV drugs on Pharmanet, a provincial medications database. The HIV/AIDS community, both in urban and rural areas, has raised serious concerns about the threat of disclosure and unintended impact of inclusion on their willingness to use life-saving drugs. The Minister's HIV/AIDS Advisory Committee believes this proposal could endanger people's jobs and personal security and cause some to decline treatment. Consequently, the committee has recommended to the Minister that broad consultation be undertaken before a decision is made.

Paddy Rodney wrote:

Many thanks for the opportunity to participate in the meeting today about the Ministry's proposed policy change for mandatory HIV positive results reporting. I believe that the process that you are undertaking to get stakeholder input is important. As per your request, I have provided written feedback here. Let me situate my remarks by noting that while I am on the Ethics Committee of BC Women's, I do not have particular expertise in issues around HIV/AIDS. My areas of research in health care ethics are around end of life decision making and the culture of health care delivery. I am, however, interested in the ethics of health policy formulation and the vulnerability of marginalized groups. In what follows, I will list and elaborate on some of the questions that I (and others) raised in the meeting today:

1. As I understand your presentation, the benefits of mandatory reporting are thought to include better mobilization of health care services, more accurate epidemiological reporting, a higher standard of pre-post test counselling, and better contact management. Nonetheless, I believe that any move to mandatory reporting would carry a moral obligation to anticipate and attenuate possible harms. This obligation applies for all British Columbians, but particularly to those who are marginalized (eg. Aboriginal people, women and men in violent relationships, refugees, people who don't speak English. troubled youth, people with substance use problems, people with disabilities).

2. One of the biggest concerns that I am left with is how mandatory reporting could affect trust in relationships between patients/clients and partners/contacts, trust in relationships between patients/clients and health care providers, and trust in relationships between providers and the public health system. For instance, how will it affect a partner/contact if they know that a positive test result may lead to their being tested and possibly entered in a provincial data base? Will the patient/client trust the physician or other health care provider to be telling the truth about what the test result data will be used for? How will the physician or other health care provider feel about having another agency take over contact management once they have reported the test results? The latter is already a concern in mandatory reporting of a patient' deemed to be dying' so that the family can be approached for a transplant

3. I do not believe that mandatory reporting will necessarily lead to better mobilization of health care services, a higher standard of pre-post test counselling, and better contact management. We operate in a health care system that is reeling after a decade of cost constraint. Unless there is ongoing attention to planning, implementation, and evaluation, there is a danger that mandatory reporting would be implemented without the supports that should accompany it. We have many examples where well-meant policy change has fallen short on implementation and has not been properly evaluated --eg. de-institutionalization of the mentally ill without follow up resources, early discharge of patients from r hospital with inadequate home care support, and harm reduction programs where needle exchange is available but detox and counselling resources are scarce. Given that mandatory reporting entails at least some limitations to patient/client autonomy, it is incumbent on policy makers to make sure that real benefits materialize.

4. As we discussed, there are groups of people where the possible risks are complex and may not be easy to predict. For example, outside intervention for women in abusive relationships carries special risks that are only now being understood --even a follow up phone call from a physician's office can be
potentially dangerous. Troubled youth, people with substance use problems, refugees, and many others have lots of reasons to distrust authority. Will they be as willing to have an HIV test if/they realize that it becomes a provincial matter rather than something between themselves and their health care provider? I know you stated that in the many jurisdictions where mandatory reporting is in place the numbers of people being tested did not drop. Were the data differentiated in terms of sub-groups? Were there differences between sub-groups? What about the effect on clients '/patients ' future experiences with health care delivery? The positive test result is just a starting point in a long trajectory of experience in the health care system.

In closing, I would like to say that my comments are not necessarily an argument to abandon the proposal of mandatory testing. Rather, they are an argument to proceed with caution in considering the policy change. Just because most other jurisdictions have implemented mandatory reporting, it doesn't, follow that BC should adopt the policy without a rigorous expert review and extensive stakeholder input.

I realize that you are well aware of the issues that land others have raised today. I hope that my written feedback will be of some use.

With best wishes for your work,

Paddy Rodney
Patricia (Paddy) Rodney RN; MSN, PhD
Assistant Professor, University of Victoria School of Nursing
Faculty Associate, UBC Centre for Applied Ethics
Research Associate, Providence Health Care Ethics Services
c/o Langara College, 5th Floor, Library Building,
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Dr. Perry Kendall
PAN Working Group Members

My apologies for missing the conference call this morning however I had a matter that I needed to attend to.

I have talked extensively with both colleagues and clients here at YouthCO AIDS (all whom are between the ages of 15-29). The general consensus is that folks are against HIV Reportability, largely due to the confidentiality issues. This was thought to be of particular significance when it came to youth and young people. Many people presently living with HIV stated that the fact that they knew they could be anonymously tested was crucial to their decision to go ahead and get tested.

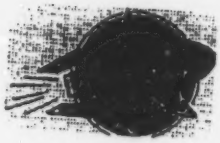
Youth undoubtedly are a more vulnerable population – all the more so if they are queer, drug users, etc. The thought that results could somehow be disclosed to health care providers and possibly parents or guardians would be a concern to many youth and enough to prevent them from getting tested.

When discussing the issue of contact notification, it was felt that simply making HIV reportable unto itself would not go far in enhancing this. There would have to be much greater resources put towards follow-through once a person was diagnosed as being HIV+. As well, this whole issue of contact notification was met with concern once again given the confidentiality concerns and the increased vulnerability of youth.

Finally, a consistent theme was that irrespective of what the ultimate decision was in terms of reportability, greater resources have to be allocated to prevention education in schools and other youth venues. Here lies some of the greatest potential for reducing the spread of the disease.

Thanks very much...

J. Evin Jones
Agency Coordinator
YouthCO AIDS Society



YouthCO AIDS Society
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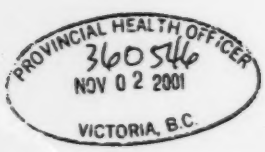
Vancouver, BC V6B 1T4
Phone: (604) 688-1441
Fax: (604) 688-4932
Email: information@youthco.org

PACIFIC AIDS NETWORK

01 October 2001



Dr. P.R. W. Kendall
Provincial Health Officer
Ministry of Health and
Ministry Responsible for Seniors
Room 3002
1810 Blanshard Street
Victoria, BC
V8V 1X4

Dear Dr. Kendall:

I am writing on behalf of the General Assembly of the Pacific AIDS Network (PAN) to state our opposition to nominal testing and partner contact tracing.

Of huge concern to the member groups of PAN is the issue of confidentiality. The release of names of persons with HIV from public health authorities who collect this information could potentially be devastating, especially for more vulnerable populations such as youth, members of rural communities, persons who use injection drugs, women, aboriginal people, and others.

Confidentiality concerns may also cause some people to avoid or delay testing. If persons at risk avoid testing, this could delay onset of treatment in infected persons and result in unwitting transmission to others.

An additional concern is that Medical Health Officers may use punitive or discriminatory measures under the Health Act against persons living with HIV if they believe them to be knowingly or unknowingly exposing others.

As regards the issue of contact notification, simply making HIV reportable unto itself will not go far in enhancing this. At this point there is no indication that the resources necessary to ensure effective and supportive contact notification have been or will be put into place.

The members of the Pacific AIDS Network appreciate your stated commitment to community consultation on this issue. We anticipate that the concerns articulated in this letter will inform any and all future government decisions made regarding reportability.

Yours truly,

Jennifer Ervin Jones, Member
PAN Working Group

PACIFIC AIDS NETWORK c/o AIDS Vancouver Island 1601 Blanshard Street
Victoria BC V8W 2J8 TEL: 250-881-5863 / FAX: 250-920-4221

Appendix C
Legal Opinion on Confidentiality and Reportable Infectious Disease

Communicable Diseases – The Duty to Report and Refrain from Further Disclosure
(Section 6.1 of the Communicable Disease Regulation)

- section 6.1 of the Communicable Disease Regulation ("the Regulation") provides:

  "6.1 Where a person voluntarily submits himself to testing or examination for a communicable disease and, as a result of that voluntary test, another person is required to make a report to the medical health officer under section 2 or 3, no person shall disclose or permit to be disclosed to any person other than the medical health officer information contained in the report or the results of an examination or test, without the written consent of the person who so volunteered".

- it is the position of the Provincial health officer that section 6.1 of the Regulation only applies respecting reportable communicable diseases for which a person has voluntarily submitted to testing or an examination (reportable communicable diseases are those listed in Schedules A and B of the Regulation).

- it is the position of the Provincial health officer that those individuals mandated not to disclose by the words "no person shall disclose or permit to be disclosed" contained in section 6.1 of the Regulation include:

  -the lab that conducts the testing and is aware of the test results (this includes owners and employees of the lab);

  -the physician who orders the tests and receives the report of the test results (this includes the owners and employees of the physician's practice);

  -the medical health officer (this includes employees and delegates of the medical health officer);

  -any individual, who as a result of the voluntary test, knows or suspects that an animal or another person is suffering from or has died from a communicable disease; and

-the Provincial health officer (this includes employees and delegates of the Provincial health officer).

- Section 104 of the Health Act provides:

"104(1) A person who contravenes this Act or a regulation...commits an offence.

(2) Unless a lower penalty is specified by regulation or this Act, a person who
commits an offence under subsection (1) is liable on conviction to the following:

(a) in the case of an offence that is not a continuing offence, a fine of not more than $200,000.00 or imprisonment of not longer than 12 months, or both...".

Examples of Application of s.6.1 of the Communicable Disease Regulation

- there is no contravention of section 6.1 of the Regulation if a laboratory returns to an ordering physician test results that indicate the physician's patient has or may have a communicable disease. The physician is not a third party because the physician ordered the test on behalf of the patient and the patient consents to the test result being returned to the physician.

- there is a contravention of section 6.1 of the Regulation if, without the written consent of the patient, a physician (or the physician's employee) releases information contained in the results of an examination or test respecting a communicable disease or possible communicable disease.

- there is a contravention of section 6.1 of the Regulation if, without the written consent of the patient, a laboratory releases to a third party researcher, information contained in the report to the medical health officer respecting a communicable disease or possible communicable disease, or information contained in the results of an examination or test respecting a communicable disease or possible communicable disease.

- there is no contravention of section 6.1 of the Regulation if the Provincial health officer releases to the BC Centre for Disease Control and Prevention Society ("the BC CDC") information contained in lab the report to the medical health officer respecting a communicable disease or possible communicable disease, or information contained in the results of an examination or test respecting a communicable

disease or possible communicable disease. Section 3 (2) of the Health Act provides:

"3(2) The Provincial health officer must monitor the health of people of British Columbia and provide to the people of British Columbia information and analyses on health issues."

The Provincial health officer is statutorily mandated to investigate and analyze the incidence of communicable disease in the population of British Columbia. To perform its duties the Provincial health officer delegates to its administrative arm, the BC CDC certain duties. While such a delegation occurs, the information remains within the care and control of the Provincial health officer. It is appropriate for the Provincial health officer to release information to the BC CDC with a view to having the BC CDC contact the patient to determine whether they will participate in a research study.

Appendix D
Health Act Provisions and Penalties

Health Act Communicable Disease Regulation
http://www.qp.gov.bc.ca/statreg/reg/H/Health/4_83.htm#section6.1

Voluntary testing
6.1 Where a person voluntarily submits himself to testing or examination for a communicable disease and, as a result of that voluntary test, another person is required to make a report to the medical health officer under section 2 or 3, no person shall disclose or permit to be disclosed to any person other than the medical health officer information contained in the report or the results of an examination or test, without the written consent of the person who so volunteered.

Health Act
http://www.qp.gov.bc.ca/statreg/stat/H/96179_01.htm#section104

Offence and penalty
104 (1) A person who contravenes this Act or a regulation, bylaw, order, direction or permit under this Act commits an offence.

(2) Unless a lower penalty is specified by regulation or this Act, a person who commits an offence under subsection (1) is liable on conviction to the following:

(a) in the case of an offence that is not a continuing offence, a fine of not more than $200 000 or imprisonment for not longer than 12 months, or both;

(b) in the case of a continuing offence, a fine of not more than $200 000 for each day the offence is continued or imprisonment for not longer than 12 months, or both.

Appendix E
Annotated Bibliography
Partner Notification and HIV/AIDS

Prepared by
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May 2001

1. Bayer, R., and Toomey, K.E., **"HIV prevention and the two faces of partner notification,"** *American Journal of Public Health*, v.82, n.8, (1992), pp. 1158-1164.

   This paper is a conceptual clarification delineating the difference between "partner notification" and "the duty to warn." Partner notification is a well-proven public health initiative rooted in the ethical principles of index patient anonymity and voluntariness. The duty to warn is an entirely different approach and is concerned with protecting an identified third party that is in immanent risk of serious bodily harm. Confusion between these two distinct approaches leads many to mistake processes that are fundamentally voluntary as mandatory and those that respect confidentiality as invasive of privacy.

2. Bureau of HIV/AIDS, STD and TB Update Series, Centre for Infectious Disease Prevention and Control, **"HIV infection reporting in Canada,"** *HIV/AIDS Epi Update* (April 2000).

   This survey explains that HIV is reportable in eight provinces and two territories in Canada, with Quebec and British Columbia as the exceptions. Four provinces require HIV to be reported nominally, four require it to be non-nominally reported and two provinces have both nominal and non-nominal reporting.

3. Burr, C., **"The AIDS exception: privacy vs. public health,"** *The Atlantic Monthly*

   This article argues that traditional HIV/AIDS policies have erred because they exempt HIV/AIDS from rigorous public health attacks on disease. Because of the careful balance between public health measures and individual civil rights, society has allowed HIV/AIDS to continue. HIV/AIDS would not be able to withstand more arduous public health efforts. The focus should be on more aggressive HIV testing, reporting, and partner notification.

4. Canadian Medical Association, **"Policy Statement on Acquired Immunodeficiency Syndrome,"** (Update 2000).

"The CMA Code of Ethics (article 22) advises physicians that disclosure of a patient's HIV-status to a spouse or current sexual partner may not be unethical and, indeed may be indicated when physicians are confronted with an HIV-infected person who is unwilling to inform the person at risk. Such disclosure may be justified when all of the following conditions are met: the partner is at risk of infection with HIV and has no other reasonable means of knowing the risk; the patient has refused to inform his or her sexual partner; the patient has refused an offer of assistance by the physician to do so on the patient's behalf; and the physician has informed the patient of his or her intention to disclose the information to the partner."

5. Chevernak, J.L., and Weiss, S.H., **"Sexual partner notification: attitudes and actions of HIV-infected women,"** *V International Conference on AIDS*, (Montreal, June 1989), [abstract DP4].

"A study of 25 HIV-positive women in New Jersey showed that 68% of them were willing to give the names of their sexual partners to the health department as long as their (i.e., the index patients') confidentiality was maintained. Only 20% of the women would agree to partner notification if their names were disclosed to the partner."

6. Dimas, J.T., and Richland, J.H., **"Partner notification and HIV infection: misconceptions and recommendations,"** *AIDS & Public Policy Journal*, v.4, n.4, (1989), pp. 206-211.

This article explains the differences between patient referral and provider referral. The advantage of patient referral is that it is very cost effective, but there is no quality assurance and the index patient's confidentiality is necessarily compromised. Provider referral is more expensive but it can guarantee the index patient's confidentiality, it is also a lot more effective. There are many misconceptions about partner notification but this does not appear to deter people from getting tested. Guiding principles for partner notification should be voluntary participation, confidentiality, accessibility, quality assurance, information provided, and targeted services.

7. Estermann, J., and Rutz, R., **"Trends of HIV infections using the anonymous mandatory reporting system and other data sources in Switzerland and in the Federal Republic of Germany,"** *Soz Praventivned*, v. 37, (1992), pp. 73-78

Switzerland and the Federal Republic of Germany both have anonymous mandatory HIV reporting systems. Data is collected from laboratory reports, blood donations, and physician reporting.

8. Fenton, K., Adler, M., Giesecke, J., et al., **"HIV partner notification in England: results of a national evaluation program,"** XI International Conference on AIDS. (Vancouver, July 1996), [abstract ThC4625].

Out of 70 eligible patients 158 contacts were named (ratio 2.3), with 71 notified, and 45 receiving testing and counseling. Out of these there were 8 new positives who were previously unaware of their infection (18%).

9. Fenton, K., and Peterman, T.A., **"HIV partner notification: taking a new look,"** *AIDS*, v11, n.13, (1997), pp. 1535-1546.

This literature review provides an overview of the rationale for HIV partner notification and summarizes the evidence concerning its effectiveness. The authors examine the practical limitations of partner notification and explore possible strategies for overcoming these. They also identify certain areas relevant to partner notification that need more research. [most of the articles highlighted with [*] are from this article.]

10. Fleming, P.L., et al., **"Guidelines for national human immunodeficiency virus case surveillance, including monitoring for human immunodeficiency virus infection and acquired immunodeficiency syndrome,"** *MMWR*, 48, RR13, (December 10, 1999), pp.1-28.

This document is the U.S. Center for Disease Control's guidelines for surveillance of HIV and AIDS. It recommends that all U.S. States extend their current AIDS surveillance activities to include HIV. Expanded surveillance will provide additional data about HIV-infected populations to enhance local, state, and federal efforts to prevent HIV transmission, improve allocation of resources for treatment services, and assist in evaluating the impact of public health interventions. There is an important section on the effect of making HIV nominally reportable and the evidence about testing behaviours. There is no strong evidence that people would not be tested simply because HIV is reportable.

11. F/P/T AIDS Working Group on Partner Notification, **"Guidelines for practice for partner notification in HIV/AIDS,"** (January 1997).

These guidelines provide some useful definitions, 10 principles for partner notification, specific program issues and specific recommendations for evaluations.

12. Giesecke, J., Ramstedt, K., Granath, F., et al., **"Efficacy of partner notification for HIV infection,"** *Lancet*, v. 338, (1991), pp. 1096-1100.

This study tracked 365 HIV-seropositive index patients who reported 564 sexual or needle-sharing contacts. 390 contacts were located and counselled, with 350 known test results. Of the 350 known results 53

previously unknown positives were diagnosed. (Note: Contact Tracing is effective, but there was no differentiation between patient referral and provider referral.)

13. Gostin, L., and Webber, D.W., **"HIV infection and AIDS in the public health and health care systems,"** *Journal of the American Medical Association*, v.279, n.14., (April 8, 1998), pp.1108-1113.

    This article is based on the study of 600 U.S. HIV/AIDS related court cases. It looks at the legal issues around HIV testing and reporting, privacy and the duty to warn, standards of care, and discrimination.

14. Higgins D.L., Galavotti, C., O'Reilly, K.R., et al., **"Evidence for the effects of HIV antibody counseling and testing on risk behaviours,"** Journal of the American Medical Association, v. 266, (1991), pp. 2419-2429.

    "Higgins et al. Reviewed 50 studies that included data on the behavioural effects of HIV counselling and testing. All longitudinal studies of homosexual men reported reductions in risky behaviour by tested and untested men, and a few reported greater decreases by seropositive men, than by seronegative men, and those untested or unaware of their serostatus. For IDU in treatment, reductions in injecting drug use and sexual risk behaviours were found after HIV counselling. Substantial risk reduction by heterosexual couples with one infected partner was noted; however, findings amongst other heterosexuals at increased risk were scarce and mixed."

15. Hoffman, R.E., Spencer, N.E., and Miller, L.A., **"Comparison of partner notification at anonymous and confidential HIV test sites in Colorado,"** *Journal of Acquired Immune Deficiency Syndromes and Human Retrovirology*, v8, (1995), pp. 406-410.

    This Colorado study compared the performance of partner notification between persons testing either anonymously or confidentially. It also compared rates of HIV testing and seropositivity among partners. During this 18-month study there were 552 positive HIV antibody tests. The average number of successfully contacted partners was 30%-50% greater among the confidential site index patients than the anonymous site index patients. Furthermore, the seropositivity rate in newly tested partners of confidential site index patients was more than twice the rate in partners of anonymous test site index patients. However, when this analysis was restricted to gay and/or bisexual male index patients the results were the same as for the total group.

16. Jones, J.L., Wykoff, R.F., Hollis, S.L., et al., **"Partner acceptance of health department notification of HIV exposure, South Carolina,"** *Journal of the American Medical Association*, v. 264, (1990), pp. 1284-1286.

"In South Carolina, Jones et al., studied the acceptability of health department notification in an anonymous questionnaire to partners notified of their exposure during the preceding 2 years. Of the 202 partners notified, 132 (65%) were locatable and completed the questionnaire. When asked whether they thought the health department did the right thing in telling them about their exposure, 87% responded, 'yes'; when asked whether they health department should continue to notify persons exposed to HIV, 92% agreed. Responses were similar for homo-/bisexual men, hetrosexuals, and IDU, man and women, and whites and blacks."

17. Kamb, M.L., Rhodes, F., Bolan, G., et al., **"Does HIV/STD counselling work? Results from a randomised controlled trial (Project Respect),"** *Fourth Conference on Retrovirus and Opportunistic Infections*, Washington, DC, January 1997 [abstract 382].

This study "evaluated the efficacy of HIV counselling in increasing condom use and reducing STD in a randomized controlled trial... After 6-months, 143 (9.8%) participants in the educational control group had new STD, compared with 107 (7.3% in prevention counselling and 98 (6%) in enhanced counselling. Condom use was significantly higher and the number of sexual partners fewer in the enhanced and prevention counselling groups, compared with the educational control group."

18. Kamenga, M., Ryder, R.W., Jingu, M., et al., **"Evidence of marked sexual behaviour change associated with low HIV-1 seroconversion in 149 married couples with discordant HIV-1 serostatus: experience at an HIV counselling center in Zaire,"** *AIDS*, v. 5., (1991), pp. 61-67.

This study found that discordant couples who were offered intensive counselling resulted in substantially increased condom use—from <5% at baseline to 71% at 1-month follow-up and 77% at 18-month follow-up.

19. Klein, S.J., Birkhead, G.S., and Wright, G., **"Domestic violence and HIV/AIDS,"** *American Journal of Public Health*, v. 90, n. 10, (October 2000), p. 1648.

The letter explains the necessity for those contemplating partner notification to seriously consider the possibility that the index patient could be vulnerable to domestic violence. It explains New York legislation that requires domestic violence screening as part of pre- and post-test counseling.

20. Laboratory Centre for Disease Control: Bureau of HIV/AIDS, STD and TB Update Series. "**HIV Testing Among Canadians: 11,000-17,000 Current HIV Infections may not be Diagnosed.**" (May 1998)

LCDC estimates that a significant number of HIV is undiagnosed in Canada up to 17,000 cases.

21. Landis, S.E., Schoenbach, V.J., Weber, D.J., Mittal, M.M., et al., **"Results of a randomized trial of partner notification cases of HIV infection in North Carolina,"** *The New England Journal of Medicine*, v. 326, n. 2, (Jan 9,1992), pp. 101-106.

This study compared the efficacy of two forms of partner notification, patient referral and provider referral. In the provider-referral group 78 of 157 partners (50%) were successfully notified, whereas in the patient referral group 10 of 153 partners (7%) were notified. Of the partners notified through provider-referral 94% were not aware that they had been exposed to HIV. (Note: Provider referral was significantly more effective than patient-referral.)

22. Macke, B.A., and Maher, J.E., **"Partner notification in the United States: an evidence-based review,"** *American Journal of Preventive Medicine*, v. 17, n.3. (1999), pp. 230-242.

This article is a systematic review of the evidence concerning partner notification in the U.S. since 1980. It found conclusively that partner notification is a means of detecting infections, HIV, gonorrhea, and chlamydia among people who are at high risk but unaware of their infection. It also found fair evidence that provider referral finds more partners and turns more undiagnosed positives than patient referral.

23. Marks, G., Richardson, J.L., Ruiz, M.S., and Maldonado, N., **"HIV-infected men's practices in notifying past sexual partners of infection,"** *Public Health Rep*, v. 107, (1992), pp. 100-105.

"Marks et al., studied the self-reported practices of men infected with HIV in Los Angeles concerning notifying past sexual partners of their risk of infection. Overall 111 subjects reported a total of 926 sexual partners during the preceding 12 months; 51 partners (5.5%) were informed of their risk by the subjects. A multivariate logistic regression analysis indicated that those with the most past sex partners were least likely to attempt to notify any partner."

24. Morbidity and Mortality Weekly Report, **"Cluster of HIV- positive young women-New York, 1997-1998,"** *Journal of the American Medical Association*, v.282, n.1, (July 7, 1999), pp. 413-416.

This report explained that routine partner notification interviews revealed that 47 women in a rural New York area had unprotected vaginal sex with the same index patient. Of the 42 who agreed to be tested 13

were infected with HIV. From these women there were 84 secondary contacts with 1 out of the 50 who were tested being positive for HIV infection.

25. Nabais, I., Gonclacves, G., Ouakinin, S., Figueira, M.L., **"Disclosure of HIV infection to sexual partners: implications in relationship,"** *XI International Conference on AIDS*, (Vancouver, July 1996), [abstract C4631].

"Nabias et al., studied the implications that the index patient's disclosure of HIV status had on the sexual partnerships of 50 couples who had been together for over 6 months. They found that HIV status was frequently disclosed to main sexual partners and that disclosure did not result in seperation or disruption of the relationship."

26. Nakashima, A.K., Horsley, R., Frey, R.L., Sweeney, P., Weber, T., and Fleming, P.L., **"Effect of HIV reporting by name on use of HIV testing in publicly funded counseling and testing programs,"** *The Journal of the American Medical Association*, v.280, (Oct 28, 1998), pp. 1421-1426.

This study used the counseling and testing data from six state health departments (Louisiana, Michigan, Nebraska, Nevada, New Jersey, and Tennessee) to compare HIV testing and counseling rates 12-months before and 12-months after HIV nominal reporting was introduced. The results were that no significant declines in the total number of HIV tests provided occurred in the months following implementation of HIV reporting (other than those expected trends present before HIV reporting).

27. **"Non-return rates for HIV testing: results of a 3-month retrospective review at an STD clinic in 1999,"** Canada Communicable Disease Report, v.26-18, (Sept 2000), pp 1-4.

This retrospective study conducted in Edmonton Alberta found that 16.8% of people tested for HIV did not return for their test results. None of the tests conducted during this three-month period were positive.

28. Oxman, A.D., Scott, E.A.F., Sellors, J.W., Clarke, J.H., et al., **"Partner notification for sexually transmitted diseases: an overview of the evidence,"** *Canadian Journal of Public Health*-Supplement 1, v.85 (July-August, 1994), pp. S41-S47.

This literature review compared the effectiveness of alternate methods of partner notification for gonorrhea, chlamydia, syphilis, HIV and hepatitis B. 1) There is strong evidence that simple forms of patient assistance directed at improving patient referral, such as a telephone call, can be effective. 2) There is moderately strong evidence that provider referral results in more partners being notified than patient referral for HIV infection. 3) There is weak evidence that provider or conditional referral

is more effective than patient referral for syphilis. 4) Conflicting evidence regarding the effectiveness of provider and conditional referral compared with patient referral for gonorrhea and chlamydia. 5) There is weak evidence that trained interviewers are more effective than routine health care providers at identifying partners, but no evidence that this results in practically important benefits.

29. Patrick, D., (BCCDC) **"HIV Partner Notification for British Columbia,"** (2nd Draft, June 1999)

    This is a draft model for partner notification in British Columbia. It explains that the principles that should guide partner notification are: partner notification is integral to ongoing care, participation is voluntary, all information is kept strictly confidential, the process should be flexible and tailored to specific needs, the emotional impact of a potential exposure must be acknowledged, and appropriate and compassionate care. The rest of the document articulates the process for partner notification.

30. Pattman, R.S., and Gould, E.M., **"Partner notification for HIV infection in the United Kingdom: A look back on seven years experience in Newcastle upon Tyne,"** *Genitourin Med* (1993), v.69, pp94-97.

    This study was a retrospective analysis of health advisor and counselor records from 1985-1992. It concluded that partner notification is an effective method of ensuring that people with a very high risk of HIV infection have access to counseling and medical care. Of the 80 people referred as a result of partner notification 79 received testing, 25 were seropositive, 75 attended as a result of patient referral, and 5 as a result of provider referral. (Note: Contact Tracing definitely works but provider referral has no clear advantages over patient referral.)

31. Pavia, A.T., Menyo, M., Niler, L., and Risk, I., **"Partner notification for control of HIV: Results after 2 years of a statewide program in Utah,"** *American Journal of Public Health*, v. 83, n.10, (October 1993), pp. 1418-1424.

    This study found that of 355 named partners 279 agreed to be tested for HIV antibodies and 39 were newly seropositive for HIV. The overall seropositivity rate among those tested equaled 14% which was substantially higher than the rate found at regular testing and counseling sights which suggests that high risk populations are being reached. The data from this study demonstrate that partner notification was acceptable to most HIV-infected persons (4/5), was successful at reaching a group at high risk of HIV infection, and was most successful among injecting drug users, women, and minorities. (Note: There was no specific data pertaining to the difference between patient referral and provider referral; however, it is speculated that trained counselors would be beneficial.)

32. Peterman, T.A., Tommey, K.E., Dicker, L.W., Zaidi, A.A., Carolina, J., **"HIV partner notification: costs and effectiveness data from a multicenter randomised controlled trial,"** XI International Conference on AIDS, (Vancouver, July 1996), [abstract ThC4626].

    1070 eligible patients (100% of eligible) 1290 contacts named (ratio 1.2), with 1035 notified and 560 receiving testing and counseling, with 122 new positives who were previously unaware (22%).

33. Rothenberg, K.H., Paskey, S.J., Reuland, M.M., Zimmerman, S.I., North, R.L., **"Domestic violence and partner notification: implications for treatment and counseling of women with HIV,"** *J Am Med Wom Association*, v. 50, (1995), pp. 87-93.

    "Rothernberg et al., found that substantial numbers of health-care providers in Baltimore reported knowledge of their HIV-positive patients' experiences with domestic violence before and after notification."

34. Rutherford, G.W., and Woo, J.M., **"Contact tracing and the control of human immunodeficiency virus infection,"** *Journal of the American Medical Association*, v.259, n24, (1988), pp.3609-3610.

    This (dated) editorial emphasizes four areas of concern in relation to partner notification and HIV. 1)HIV infection is under diagnosed and therefore it is unlikely that enough contacts will be identified to disrupt the course of the disease. 2) The average length of time between HIV infection and diagnosis is likely a lot longer than the standard 1-2 years that public health routinely limits investigations. 3) The only intervention that is available to interrupt HIV transmission is behaviour modification counseling and to a more limited extent antibody testing. 4) Partner notification is labour intensive and expensive.

35. Rutherford, G.W., Woo, J.M., Neal, D.P., Rauch, K.J., et al., **"Partner notification and the control of human immunodeficiency virus infection: two years of experience in San Francisco,"** *Sexually Transmitted Diseases*, v.18,n.2, (April-June, 1991), pp107-110.

    This study focussed on opposite sex contacts of AIDS patients as a means of limiting sexual and vertical transmission of HIV. 34 partners were tested and 7 had positive HIV-antibody test results. The conclusion of this study is that provider referral is relatively expensive but its ability to target case finding, education, and counseling to women at highest risk of infection may make it potentially cost-effective for the prevention of vertically transmitted HIV infection. (Note: Provider referral was used, people choosing patient referral were excluded from the study. The majority of individuals chose patient referral.)

36. Spencer, N.E., Hoffman, R.E., Raevsky, C.A., Wolf, F.C., and Vernon, T.M., **"Partner notification for human immunodeficiency virus infection in Colorado: results across index case groups and costs,"** *International Journal of STD & AIDS*, (1993), v.4, pp. 26-32.

This is a retrospective study conducted in 1988 and looked at 231 index cases. Index cases identified 239 partners, 21% of whom were seropositive. Index cases were grouped by ethnicity, gender, sexual orientation, and injection drug use behaviour. There were no remarkable differences among groups except gay men. Gay men were more reluctant to notify partners and notified partners were more reluctant to accept testing and counseling. Overall partner notification and provider referral should be offered to all HIV infected individuals. Another unique aspect of this study is that it looked at cost implications—costs of enhanced partner notification were not found to be prohibitive. (Note: Contact Tracing works but provider referral was shown to have definite benefits: patient referral contacted 20.2% of identified partners and provider referral identified 71%.)

37. Wells, K.D., and Hoff, G.L., **"Human immunodeficiency virus partner notification in a low incidence urban community,"** *Sex Transm Dis*, v.22, (1995), pp. 377-379.

366 eligible patients (100% of eligible) 662 contacts named (ratio 1.8), with 447 notified and 447 receiving testing and counseling, with 33 new positives who were previously unaware (7%).

38. Wykoff, R.F., Heath Jr. C.W., Hollis, S.L., et al. **"Contact tracing to identify human immunodeficiency virus infection in a rural community,"** *Journal of the American Medical Association*, v. 259, (1988), pp.3563-3566.

485 contacts named (ratio of 5.3), with 290 notified and 280 receiving testing and counseling, with 46 new positives who were previously unaware (16%)

39. Wykoff, R.F., Jones, J.L., Longshore, S.T., et al. **"Notification of the sex and needle-sharing partners of individuals with human immunodeficiency virus in rural South Carolina: 30-Month Experience,"** *Sexually Transmitted Diseases*, v.18, n.4, (October-December, 1991), pp217-222.

This study occurred in rural South Carolina. There were 485 named contacts, 290 were successfully contacted and 280 accepted testing and counseling. Of the 280 tested 49 were positive for HIV-antibodies. The emphasis of this study was on a rural setting and concluded that partner notification can accurately target education and testing to people at greatest risk. Partner notification appears to be highly acceptable to at-risk individuals and results in important behavioural changes, and it may assist in following demographic changes in the HIV epidemic in a given

community. Of the 91 HIV-positive residents in this health region 49 (54%) were identified by the provider assisted program. This study evaluated the effects of education on sex and needle sharing partners of index patients who tested positive for HIV antibodies. "After notification, the mean number of sex partners per 6-month period decreased from 7.1 to 1.3 (82% reduction) for HIV-positive persons and from 4.1 to 1.9 (54% reduction) for HIV negative persons. Reports of at least some condom use increased from 0 to 80% in HIV-positive men and from 0 to 69% in HIV-negative men."

40. **"New treatments give HIV reporting added weight,"** *AiDS Alert*, (July 1997), pp. 80-83.

This article examines some of the philosophical concerns with making HIV nominally reportable in the United States. The impetus for this is the federal *HIV Prevention Act* of 1997. It explains what states would be required to do if HIV became reportable, whether name reporting would compromise civil rights, and the consequences of combining HIV, AIDS, and TB surveillance systems. There is an important mention of a two-day workshop hosted by CDC where a survey showed that concerns regarding nominal reporting were not high on the list of reasons people gave for not seeking HIV testing.